

UNITED STATES DISTRICT COURT  
SOUTHERN DISTRICT OF NEW YORK

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S.W., by her parent and natural Guardian, J.W.,  
individually and on behalf of all others similarly  
situated; B.F. by his parent and natural guardian,  
P.F. individually and on behalf of all others  
similarly situated; J.F. and P. F., by their parent  
and natural guardian, A.F., individually and on  
behalf of all others similarly situated,

Docket No.

**Affidavit**

Plaintiffs,

vs.

SHEILA WARREN, sued individually, and as  
Director of Early Intervention Services for Orange County,  
ORANGE COUNTY DEPARTMENT OF HEALTH,  
COUNTY OF ORANGE,

Defendants.

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STATE OF NEW YORK )  
 ) ss:  
COUNTY OF ORANGE )

Mary Jo Whateley, of full age, under the penalties of perjury, respectfully says:

1. I am a staff attorney with Legal Services of the Hudson Valley, Newburgh, New York.

Since in or about November 2005, I have been representing disabled children and adults in  
Orange, Sullivan, Ulster and Dutchess Counties, advocating for appropriate services and medical  
treatment.

**Plaintiff S.W.**

2. Plaintiff, S.W., is my granddaughter. She is 4 years old. In November 2005, she  
was diagnosed with autism. Since her diagnosis, I have assisted my son, Jason, and his wife,

Jessica, advocate for the provision of appropriate services through Orange County's Early Intervention and preschool programs.

3. By the time S.W. was diagnosed with autism, she had already been part of the Early Intervention program for approximately one year, receiving no services for the treatment of autism. As the documents bear out, when S.W. was evaluated for E.I. services, in addition to being completely non-verbal, she was exhibiting other classic signs of autism. These symptoms - lack of eye contact; failure to respond to her name; self-stimulating behaviors; lack of social interaction - were noted by the evaluators, but ignored, and no follow-up evaluation with a specialist in diagnosing autism was recommended. Attached as Exhibit "1" is a copy of E.I.'s multidisciplinary evaluation dated January 27, 2005.

4. Finally, after nearly a year without proper diagnosis and therapy, one of S.W.'s providers had the courage to confide in me and S.W.'s parents that S.W.'s developmental deficits may be more than simply "delays", and she should be evaluated by a neurologist. The provider requested that we not mention her suggestion, stating that Sheila Warren had specifically prohibited all EI providers and coordinators from mentioning "autism" or, if a diagnosis was "suspected", from suggesting that a child may require, or referring a child for, further evaluation.

5. In November 2005, Jason and Jessica brought S.W. to a pediatric neurologist, Dr. Ronald Jacobson, who evaluated her, and immediately diagnosed her as being on the autism spectrum. He gave her parents a prescription for 30 hours ABA therapy per week.

6. I did not attend the following IFSP meeting with my son and daughter-in-law, at which they provided the E.I. team the prescription from Dr. Jacobson. At that time, I trusted - and, I was soon to learn, so did many parents of children in E.I. - that the E.I. team would act

in “the best interests of each child”. We expected the E.I. team to immediately agree to commence provision of the services as prescribed by Dr. Jacobson. Instead, the E.I. team consented to the provision of only 6 hours of ABA per week “as a start”. When I discussed this with my daughter-in-law, Jessica, she told me that the E.I. coordinator told her that “no child in the County gets 30 hours a week”, and stated it was County policy to “start slowly” to see “how much the child can tolerate” before increasing.

7. At that point in time, I was unfamiliar with the body of evidence that existed establishing that nearly half of autistic children who received two years of early, intensive ABA therapy could recover from autism such that they would be virtually indistinguishable from their non-disabled peers. (Ex.2, p.21). Defendant Warren’s tactic of “start slowly and see how much the child can tolerate” hinted at a sympathetic consideration for the child and struck a chord with parents who want to be nurturing and not overbearing to their disabled children.

8. The difference between these parents and defendant Warren is that defendant Warren knew what the parents did not know or understand: that scientifically-based, peer-reviewed research existed which made clear that early and intensive therapy, based on the principles of applied behavioral analysis, was the only proven effective methodology for treating children with autism. It held out significant hope for improvement, and even recovery, for many young autistic children.

9. As the Guidelines, and the research they are based upon, make clear, a minimum of 20 hours of ABA therapy per week was necessary to maximize an autistic child’s potential; and

providing 10 or less hours of ABA therapy per week was virtually meaningless.<sup>1 2</sup>

10. After my granddaughter was diagnosed, I began attending local autism support group meetings to help me learn more about the disability and the available services. About this same time, I began representing autistic children, and speaking to their parents about their individual experiences. I learned that it was a common occurrence at IFSP meetings, when discussing the provision of ABA therapy, for defendant Warren and her representatives to state these words with professional conviction and authority: “Let’s start slowly; let’s see what the child can tolerate”. “Let’s not overwhelm the child.” Let’s protect the child from “too much therapy”.

11. When I look back to when my family first put their faith and trust in Ms. Warren and the County’s EI program, I am overwhelmed with anger and heartache. My granddaughter could have been - and should have been - diagnosed at one year of age. She could have been - and should have been - receiving “early and intensive therapy” for two full years as the Guidelines recommend before aging out of early intervention and into preschool. She is 4 years old now. She is still in diapers; she does not speak. She is highly intelligent; but she cannot control her self-stimulating behaviors that arise from anxiety and continual frustration at her inability to communicate. She - and every other similarly situated disabled child - deserved the opportunity to maximize her potential to live independently and to minimize her potential for developmental delay through early intensive intervention services as prescribed by federal law.

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<sup>1</sup> Such low level of therapy resulted in only 2% recovery, as opposed to 47% for those children who received 40 hours of ABA per week. (Ex. 2, p.3).

<sup>2</sup>If the defendant County’s only consideration was financial, then one could readily conclude that defendant Warren’s policy of providing 10 hours or less of ABA therapy per week to autistic children – or approving the children for more, and just providing less - resulted in a substantial waste and misallocation of money.

*See 20 U.S.C. 1471, et seq.*

11. Through the implementation of her illegal policies, defendant Warren took away Samantha's rights and deprived her of full opportunity to develop her potential, thereby altering the course and quality of her future.

12. As Congress noted, the window of opportunity exists for autistic children when they are the youngest - the exact time in their life when they will find themselves subjected to the machinations of defendant Warren. It is a travesty of justice and the epitome of immorality that defendant Warren should have been permitted to continue her blatant misuse of her position and power for so long. The tragic loss of potential for development for autistic children is incalculable - it is a loss to the individual children, their families, their communities, and our society as a whole.

13. In February 2006, Samantha's parent informed her ongoing service coordinator that they were not satisfied with the quality of speech therapy Samantha was receiving and requested a change in provider. The coordinator scheduled an IFSP meeting. I attended, as did defendant Warren. Not only was it agreed that the speech therapist would be replaced, but that Samantha's speech sessions would be increased from 2x per week to 3x per week. We were pleased that the County was receptive to our concern that Samantha was making no progress and responded by increasing her speech therapy.

14. I was about to learn what I am now certain that many other family members likewise know: because a therapy is approved and included on a child's IFSP does not mean that the child will receive the therapy timely - if at all.

15. From February 2006 until August 31, 2006 - the date Samantha "aged out" of the EI program, despite her IFSP, she received no speech therapy whatsoever. Each time my son or

daughter-in-law or myself asked when the therapy would start, we were given the same response "There are no providers available at this time." I can only surmise that my granddaughter was "punished" by defendant Warren because we, her family, expressed dissatisfaction with one of the E.I. providers and had requested that she be replaced.

16. On October 2, 2006, I sent a letter to defendant Sheila Warren, requesting that S.W. be provided compensatory speech therapy. I confirmed my understanding that there was then a shortage of speech providers, and that S.W.'s parents were willing to accept the services of a special instructor experienced in language development. A copy of the letter is annexed as Exhibit "3"). Ms. Warren did not respond to this letter.

17. On October 16, 2006, I sent a second letter to Ms. Warren requesting a response to my October 2<sup>nd</sup> letter. A copy of the October 16<sup>th</sup> letter is annexed as Exhibit "4".

18. On October 30, 2006, Senior Assistant County Attorney Matthew J. Nothnagle, Esq., sent me a letter denying my request for compensatory services for S.W., stating that, legally, the County may no longer provide such services as S.W. had "aged out". Mr. Nothnagle added that, "In any event, a large volume of services was provided to Samantha...", and went on to, basically, blame S.W.'s parents for the lack of speech therapy because they had rejected an unqualified speech provider. Lastly, Mr. Nothnagle noted that "no substitute was available" at the time. A copy of Mr. Nothnagle's October 30<sup>th</sup> letter is annexed as Exhibit "5".

19. On November 1, 2006, I responded to Mr. Nothnagle's letter of denial and addressed each of his bases for denial. In addition, I attached a copy of a guidance document from the United States Department of Education, Office of Special Education and Rehabilitative Services, dated August 19, 2003, stating, in relevant part, that a child having "aged out" of Early Intervention into the Preschool program - as S.W. had done - would not alter her right to seek

compensatory services under the Early Intervention program.

20. Further, I informed Mr. Nothnagle of my belief that the shortage of speech providers in Orange County may be partly the result of a policy instituted by Sheila Warren which imposed an unreasonable condition upon independent providers who wished to provide services through Early Intervention. I based my belief on conversations I had had with many related service providers who had previously had contracts with Orange County to provide therapy to children in the Early Intervention or Preschool programs. Each of them relayed basically the same information to me: that they previously had contracts with Orange County; that they were forced to discontinue their contracts with Orange County because Sheila Warren had told them she would not renew any provider's contract unless they agreed to maintain an arbitrary number of cases. A copy of my November 1<sup>st</sup> letter, and a copy of the OSEP guidance document, are annexed as Exhibit "6".

21. I informed Mr. Nothnagle of my family's desire "to avoid protracted litigation of this issue" and requested that he reconsider the matter in light of the OSEP guidance on this issue.

22. In responding, Mr. Nothnagle reiterated the County's position that - despite the fact that S.W. had been approved to receive speech 3x per week, yet had not been provided *any* for a period of *6 months* - his client considered the matter moot. He did not address OSEP's guidance document which I had provided him.

23. After my granddaughter was diagnosed with autism, I began researching the Early Intervention program and determined that, pursuant to New York State Guidelines, which had been prepared specifically for the Department of Health's Early Intervention program, it was strongly recommended that a *minimum* of 20 hours of intensive behavioral therapy be provided each child with a diagnosis of autism. While the Guidelines Panel noted that other therapies, in

and of themselves, were not found to be particularly “harmful”, the authors of the Guidelines stated that the “harm” of providing any other therapy to an autistic child was the indirect harm of “lost time” in providing the only proven therapy – ABA. Attached as Exhibit “7” are relevant sections of the NYS Guidelines.

24. Since my granddaughter’s diagnosis in November 2005, I have had the opportunity to represent and advocate for many children on the autistic spectrum here in Orange County. Many parents have told me that their disabled children have been approved for Early Intervention and Preschool services, but are not receiving them because of a “lack of providers” - of speech, ABA, OT and PT.

25. Since November 2005, I have met with and had conversations with parents of disabled children in the E.I. and Preschool programs, as well as E.I. and Preschool service providers and coordinators from various agencies throughout Orange County. The stories they have recounted to me were consistent and horrific.

26. I commenced researching County and State documents to aid me in understanding defendant Warren’s duties and obligations and the degree of discretion she enjoyed in carrying out her duties. I found no support whatsoever for the policies and practices that she had unilaterally developed and was imposing on the professional therapists under her apparent control.<sup>3</sup> Instead, what I found astounded me - documents evidencing that defendant Warren intentionally and maliciously misused her position and authority to prevent autistic children

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<sup>3</sup>Several providers told me that, whenever someone would “challenge” her or her policies at a provider meeting, rather than engage in open discussion, she would verbally slap them down and then state “Remember who you work for.” In one instance that I know of, defendant Warren actually terminated a provider’s contract for supporting a parent’s request that a child continue receiving home-based services from which he was benefiting and, thus, going against her often-stated view that “autistic children belong in center-based programs”.



from receiving the opportunities to which the law entitled them, as follows:

- (a) Defendant Warren does not properly refer children who exhibit signs of autism for proper evaluation and diagnosis;<sup>45</sup>
- (b) Defendant Warren prohibits E.I. therapists and coordinators from even suggesting to parents that they may want to have their child further evaluated.<sup>6 7</sup>
- © By avoiding or delaying a child's diagnosis with autism, defendant Warren prevents or delays each such child's from receiving necessary services;
- (d) Defendant Warren does not follow even the minimum recommendation of the Guidelines' for provision of ABA therapy;
- (e) When a provider or parent asks about the Guideline recommendations, defendant Warren responds "They are only guidelines; we don't have to follow them."
- (f) When an IFSP team does approve an autistic child for a higher level of ABA therapy than the norm, defendant Warren's then implements her strategy of "start slow; increase gradually".
- (g) In a memo dated March 16, 2000, defendant Warren characterized the shortage of speech therapists in Orange County as a "crisis"; (See, Ex.8);<sup>8</sup>

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<sup>4</sup> This prohibition is especially heinous because it plays upon a parent's fear and denial. Even a parent who does suspect their child is autistic - and many of them do - does not want to *believe* their child is autistic, so when the evaluation report does not even mention that autism is suspected, a parent breathes a sigh of relief, and readily accepts that their child is merely "developmentally delayed", grasping onto the implication that the "delay" will be addressed through E.I. services (speech, OT, PT, etc.) and the child will eventually "catch up".

<sup>5</sup>Early Intervention Memorandum 1999-2, dated 12/10/99 and forwarded to NYS Early Intervention Officials, reiterated the importance of assisting the family in obtaining an accurate diagnosis. (See, attached excerpt - Ex. 9, p., 3).

<sup>6</sup>Basically, defendant Warren places the therapists in the untenable position of pretending they don't see the proverbial big, white elephant in the family's living room.

<sup>7</sup>Fortunately, some therapists are courageous enough to whisper their concern. Such was the case with S.W.

<sup>8</sup>In her 3/16/00 memo, defendant Warren noted that some children had been waiting for speech services since October 1999.

- (h) In 2003, defendant Warren instituted a “minimum caseload” policy that significantly reduced the number of County-approved E.I. and Preschool providers of all therapies (See, Ex. 10);
- (i) In January 2005, Orange County published its “Community Health Assessment 2005-2010”. Defendant Warren participated in the development of the Assessment. On Page 14, the Assessment reports the need for additional providers for related services in the E.I. and Preschool Programs, “especially in speech pathologist and Special Education Itinerant Teachers (SEIT)”,<sup>9</sup> and that **the need for providers is evidenced by waiting lists (sometimes as long as 4-5 months) which result in service delays.**” (Emphasis added). (See, Ex.11).
- (j) In January 2006, Sheila Warren appeared at the County Legislature’s Mental Health and Hygiene Committee meeting. Defendant Warren was directly questioned by County Legislator Paduch as to whether there are “any ongoing problems now with different providers that are in need, like in speech.”  
  
According to the Minutes of the meeting, “Ms. Warren responded that yes, there will always be difficulty with speech and they just added some new contractors. We’re constantly working with a growth factor in that. Right now the rating is just maybe two children, but that could change tomorrow. **So we’re not hurting for people, and we are adding to make sure that the program staff is adequate.**”<sup>10</sup> A copy of the Minutes of the January 26, 2006, meeting are annexed as Exhibit “12”.
- (k) Despite the critical shortage of speech therapists in defendant County’s E.I. and Preschool Programs, and the reported “4-5 month waiting list” for services, in April 2007, E.I. staff inform Susannah Hatlenboer, a licensed speech therapist, that under no circumstances will she be able to obtain an independent contract to provide speech therapy to children in the E.I. or preschool program. (See, Hatlenboer Affidavit).
- (l) Many children in E.I. programs are aging out of the E.I. program without having received the therapies stated in their IFSP’s.

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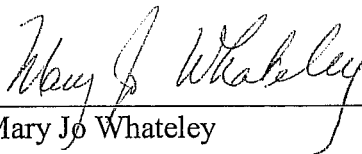
<sup>9</sup> In Orange County, ABA therapy apparently has been provided primarily by special education itinerant teachers (SEIT’s).

<sup>10</sup> Upon information and belief, the source of my information being conversations with E.I. service providers and service coordinators, at the time Ms. Warren made these statements before the Orange County Health & Mental Health Committee, many children in the E.I. and preschool program were going without speech therapy due to the lack of sufficient providers.

- (m) Once a child has “aged out” of E.I., parents are told that they no longer qualify to receive the services to which they had been entitled, but failed to receive, as the result of the “lack of providers”.
- (n) Once an autistic child transitions to the Preschool program, E.I. representatives attend the CPSE meetings and attempt to coerce parents into agreeing to a “center-based” placement, without due consideration of the child’s unique needs or abilities and without consideration of the least restrictive environment.
- (o) Most disturbing is defendant Warren’s stated position that “[I]f an autistic child recovers, then he wasn’t autistic.” (See, McGuire affidavit).

26. Defendant Warren’s *modus operandi*, outlined above, result in predictable and verifiable outcomes, amongst them being that (1) rarely, will an autistic child in Orange County be diagnosed early enough to receive the *quantum* of therapeutic interventions through the Early Intervention Program that the E.I. Guidelines state are necessary to maximize a child’s potential for development and, (2) once properly diagnosed, an autistic child in Orange County may never receive the medically-necessary therapies as prescribed by their treating physicians and, instead, receive the minimum amount of services to which defendant Warren is able to manipulate a trusting and unsuspecting parent into accepting.

27. I strongly believe that defendant Warren has systematically and intentionally sought to limit the provision of EI and preschool services to autistic children here in Orange County, thus depriving them of their legal entitlements, as well as denying these children a free and appropriate education in the least restrictive environment, and respectfully request that the Court enjoin her from continuing her pattern of illegal and harmful conduct.

  
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Mary Jo Whateley

Sworn to before me this \_\_\_\_ day of  
August, 2007.

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